



Community-based participatory research: a collaborative study to measure capabilities towards recovery in mental health community organizations

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Abstract

Objective: The purpose of this article is to offer a theoretical review on community based research, namely about collaborative processes and qualitative participatory methodologies, and to present an application of this framework to the research design. *Method:* It is provided a review on community-based research methodology, university-community partnerships, and is described the qualitative participatory methodology used in one collaborative study. *Conclusion:* following the partnership guidelines for collaborative community-university research, we highlight the participatory and qualitative process that intended to develop a measure of user's capability gains fostered by mental health community based organizations.

Keywords: participatory community research; mental health organizations; qualitative methods.

Introduction

Community psychology literature from the last decade has stressed the relevance of developing strategies of bridging science and practice (Wandersman, Kloos, Linney, & Shinn, 2005) and of selecting adequate methods to advance towards more community centred research models (Wandersman, 2003). Linney (2005) has analyzed models that aim and lessening this science-practice distance and fostering collaboration in the community research process. The proposals found, always focus on program's implementation and some underline the importance of community-university partnerships' development.

Dalton, Elias and Wandersman (2001), consider that "through collaborative research and action, community psychologists seek to understand and to enhance quality of life for individuals, communities and society" (p. 5).

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Community psychology is a discipline guided by values; there are seven core values (Dalton et al., 2001; Ornelas, 2008), that are the basis for the definition of questions, hypotheses, objectives and methods, both in research and intervention (Table 1). For the purpose of this paper we will only highlight the value of Collaboration.

Collaboration and Community Strengths. According to Dalton et al. (2001), it relates to the relationships created between community psychologists and the citizens or members of the community. The authors consider that a collaborative relationship has certain characteristics, such as, shared processes of decision-making, definition of objectives and knowledge from both parties, in this case academics and community members, is equally valued. The life experience of the citizens is considered as important as the academic expertise of the community psychologist, because both bring knowledge and resources to the process. Thus, collaboration is important for the choice of methodology in research and intervention.

Collaboration is also deeply connected with the ecological perspective, while a fundamental paradigm for research and intervention in community psychology. James Kelly argues that the ecological approach is linked to contextualism, which refers that “knowledge is relative to a given empirical and theoretical frame of reference and that we are implicitly embedded in the world we observe” (Kelly, 2006, p. 171).

Trickett and Ryerson Espino (2004) suggest that collaboration in community research works as a transition from the individual to community-level research, and mention a group of preconditions for the collaborative process: a mutual goal, parity among participants, shared participation, Riger (2001) also places trust as a fundamental quality in community research, especially when researchers entered a community, gathered data and left, leaving a feeling of treason in the community. “This kind of research can be exploitive, benefiting only the researcher and giving nothing back to the community” (Riger, 2001, p. 46-47).

For the science-practice debate, Tebes (2005) purpose a shift in the conceptualization and practice of research: an idea of perspectivism. The author has highlighted that in logical empiricism, the research context, the points of views of the participants involved in the research, and the multifaceted research process implementation, are always described minimally as an expression of relative value to the paradigm. Therefore, ecological approach it is crucial to gather knowledge using pluralistic methods of empirical observation (Ryerson Espino & Trickett, 2008; Tebes, 2005). This is considered the most appropriate way for characterizing knowledge about community systems (Kelly, 2006).



Table 1
Community Psychology Core Values

Values	Characteristics
Individual Wellness	Refers to the physical and psychological health, the necessary socio-emotional coping skills to promote health and personal well-being, also identity development, personal goals achievement.
Sense of Community	Regards the feeling of belonging and mutual commitment, which links individuals in a collective unity. There is a feeling of interdependence within this collective unity, in which the elements will take actions to strengthen the community.
Social Justice	There must be an equal and fair access to resources by all members of society. The community psychologist must advocate for the balance of power, equality in the access to resources, opportunities, rights and obligations in the community.
Citizen Participation	Decision-Making processes available to all members of a community, in an atmosphere of promotion for the collaborative and active participation of the citizens. Not only at an individual level, but also at a community level, the communities should participate in defining the problems or issues that affect them, and in deciding how to solve them, is fundamental to the community psychology's perspective.
Collaboration and Community Strength	This is considered has the most distinctive value of Community Psychology. It relates to the relationships created between community psychologists and the citizens or members of the community with whom they work. Although the community psychologist may be viewed as an expert, he seeks to establish a collaborative relationship with the citizen. The collaborative relationship style has certain characteristics, such as shared processes of decision-making, definition of objectives and knowledge from both parties are equally valued. The life experience of the citizens is considered as important as the academic expertise of the community psychologist, since both bring knowledge and resources to the process. This value is important for the choice of methodology in research and intervention.
Respect for Human Diversity	This value enlightens the importance of human diversity for the communities, in all its forms, gender, age, sexual orientation, socioeconomic status and others. The respect is reflected, in the community psychologist search for strengths and resources among all communities, cultures and marginalized populations. An important aspect is the acquired notion that diversity demands for the adaptation of methods to the community in study.
Diversity Empirical Grounding	For a community psychologist a theory and research that do not have an empirical basis on the experiential life of the community are incomplete. So the community psychologist seeks to define, understand, and address community problems and issues in ways that can be studied in research. Research is both valid through quantitative and qualitative methods; the relationship with the community is built on a collaborative style.

Note. Adapted from *Community Psychology: Linking Individuals and Communities*, Dalton et al. (2001).

Kelly (2006) postulates four characteristics as necessary constituents of the ecological approach: theoretical propositions, the social constructions of ecological knowledge, the collaborative style, social processes. We will focus on the collaborative style. Kelly (2003) and Ryerson Espino and Trickett (2008) consider that the proposed relationship between scholars and citizens must rely on two core values: *commitment* and *reciprocity*. Kelly (2006, p. 176) says: “the assumed benefit of the collaborative style is that the discovery of information about structures, roles, and norms expressed in context will enhance the authenticity, the validity, and, therefore, the usefulness of the research”, and Tebes (2005, p. 222) reinforces, that situated knowing “provides encouragement for opening up alternative ways to scientific inquiry, such as narrative, case study, and participatory action research (...)

legitimizing the inclusion of diverse voices, based on gender, race, age, ethnicity, class, and so on, into the research process, because to do so is to do better science”. This collaborative effort is expected to reduce the perspectival discrepancy between observation by the researcher’s objective measures and the subjective reports of the participants in the research.

Also Trickett and Ryerson Espino (2004), state that the validity and quality of the research is enhanced, when the research team works with local knowledge and how such knowledge and may exert impact on the local community (Wandersman, Kloos, Linney, & Shinn, 2005).

Collaborative Research Partnerships

According to Suarez-Balcazar et al. (2004), this form of collaborative partnership is primordial in community research and action. In these partnerships, the university researchers’ work in collaboration with a variety of settings and programs by involving agency staff, or members of grassroots organizations, offering a new vision of how universities and communities can work together. These authors provide a definition for this type of collaboration as a mutually beneficial and well-defined relationship between two or more organizations to achieve common goals, where academic researchers work in collaboration with a variety of community settings and programs (e.g. community groups and organizations, schools, health services and agencies) to solve social problems and to support social change efforts.

Roussos and Fawcett (2000) consider collaborative partnerships a prominent issue for community health improvement. The community residents or organization representatives participate actively in the research team and the research agenda is guided by the needs of the community, and not only by the researcher’s needs. Bond and Keys (1993) describe this process as co-empowerment. Trickett and Ryerson Espino (2004) distinguish between conducting research in the community and conducting it with the community, and add, conceptually, a temporal dimension to collaborating in the context of an evolving, long-term relationship. In their ecological perspective, “collaboration is facilitated in all phases of the work, with mutual benefit for all partners involved. The process is intended to be empowering, to attend social inequalities, and is cyclical and iterative over time” (Trickett & Ryerson Espino, 2004, p. 15).

Community-based participatory research (CBPR) was defined by Minkler and Wallerstein (2003) as a collaborative approach that implies all partners in the research process



in equal terms, and recognizes each one contribution. Recently, Stacciarini, Shattell, Coady and Wiens (2011), made a review on study papers using community-based participatory research; a number of articles focused on issues regarding collaboration development, like frequent team meetings, phone calls, focus groups, feedback forms and update letters that appear as critical aspects in the maintenance of commitment and reciprocity.

Table 2

Collaborative Research Partnerships

Characteristics
<i>To develop a relationship based on trust and mutual respect</i> among a diverse set of stakeholders (funders, directors, staff, leaders, residents, among others) that must be involved and informed throughout the partnership building process. Trust requires a careful timing in accessing the setting, and the establishment of a common vision and goals, and clarification of expectations.
<i>To maximize, use, and exchange resources</i> that must be brought to the research relationship by each partner (access to resources like grant funding, knowledge of research literature and methods, technology, and experiential community and cultural and contextual knowledge of the setting or community, key informants and networks) in order to create a balanced relationship.
<i>To build a two-way learning relationship</i> recognizing that there is knowledge in both the university and in community.
<i>To establish open lines of a communication system.</i> In a collaborative process goals and expectations may evolve requiring a frequent revision and negotiation between the parties. because goals and expectations may evolve along the process with the need for open and frequent revision and negotiation
<i>To respect and celebrate diversity</i> that is imbedded in community is essential in the relationship building. Diversity also includes the development and the use of culturally sensitive and appropriate research instruments and protocols
<i>To learn about the culture of the organization</i> listening mutually because each community organization has its own cultural features, background, areas of expertise; and academic contexts also have their values, identity and traditions
<i>The research collaboration is based on the needs of the community.</i> For the partnership to be successful, it needs to meet a need of the community organization which is likely to result in increased use of findings and social action, and also reach the academic needs such as thesis, reports and publications
<i>Understand the multidisciplinary nature of partnerships</i> engaging individuals from different disciplinary backgrounds, as well individuals with diverse cultural and historical experiences (e.g. individual or collective experience in dealing with the social and political impact of the issue of interest)
<i>Use both qualitative and quantitative research strategies</i> in order to equip the research agenda with multiple levels of analysis allowing to describe quantitatively one community and also to obtain rich stories and voices that help to explain or illustrate those numbers in innovative ways
<i>To share accountability of partnership success and opportunities</i> as well leadership and control of processes and structures. This feature may be done by joint reports, shared publicity in academic and community fields, and shared conflict resolution of problems and misunderstandings during the research intervention development process.
<i>Note.</i> Adapted from <i>University-Community Partnerships: a Framework and an Exemplar</i> , Suarez-Balcazar et al. (2004).

Based also on a literature review of collaboration models, Suarez-Balcazar et al. (2004) highlighted 10 common aspects that characterize the development and maintenance of community collaborative partnerships (Table 2). Subscribing their vision, through a collaborative partnership, the research relevance is considerably enhanced by this ecological

validity processes and the community settings also gain an empowered status offered by the mainstream academic scientific recognition.

Participatory Action Research

In Prilleltensky and Nelson's (2002) perspective, participatory action research (PAR) has an explicit focus on social change and integrates aspects from participatory research and action research. They refer that PAR is based on empowerment and social justice values, and that researchers strive to engage participants as "co-researchers" and "co-analysts" in the development of knowledge (Chesler, 1991; Prilleltensky & Nelson, 2002).

Chesler (1991) presents participatory action research as an example of new scientific roles and techniques to generate useful knowledge for community organizations. The author considers that the uses of PAR findings are more consistent with the community organizational structures, and with their action needs. Nelson, Ochocka, Griffin, and Lord (1998, p. 888), have proposed a definition for participatory action research as "a research approach which consists of the maximum participation of stakeholders, those whose lives are affected by the problem under study, in the systematic collection and analysis of information for the purpose of taking action and making change."

Based on a review by Trickett and Ryerson Espino (2004), participatory action research provides both a set of community research and action goals (shared ownership, learning, and, action) and a set of criteria to assess the congruency between rhetorical and practice, namely: context familiarization; problem identification; formulation of the research design; centring on issues of community concern; data collection and analysis; and action implementation. In PAR approaches, the main issues are not the data-gathering techniques, but rather the collaborative conditions of goal setting, the processes of data gathering and analysis, and the research findings utilization based on trust, demonstration of community groups' experiential knowledge, joint agendas, and commitment (Chesler, 1991).

The participatory research that focuses on the group level can examine the empowering or disempowering qualities of relationships, groups, and organizations and the resulting outcomes (Prilleltensky & Nelson, 2002). PAR is also important in order to conduct research on conditions that capacitate people, who experienced disabilities and disadvantages, to achieved social integration (Bond & Keys, 1993).

Because the disadvantaged people that are the focus of research must be well represented in the research endeavour, Nelson et al. (1998), developed guidelines to implement the process, namely by creating structures which are central vehicles for



communication in the participatory complexity (e.g. summary bulletins or feedback sessions). The authors propose to have: a) a research steering committee to supervise the development of the research project, functioning like board members and making decisions (e.g. negotiation and consensus), and b) a research team responsible to carry out the research tasks, both collecting and analyzing.

Methodological Pluralism

In order to overcome the distance between science outcomes and intervention needs, a pluralistic approach is another proposal that has been referred in the literature (Barker & Pistrang, 2005, Kelly, 2003, Trickett & Ryerson Espino 2004), which is based on the idea that the research paradigms are determinant for the data gathering methods choices, in the research production. Chesler (1991) highlights that inductive and qualitative approaches can offer: valid insights, systematic understanding, and orientation for intervention and action.

Giving the experiences of disadvantaged people, that participates in multiple social contexts, Prilleltensky and Nelson (2002) advocate that the meaning of those experiences to people is the most relevant rather than the relationship between the different expressions of their experiences.

Table 3
Criteria and Values Applicable to Pluralistic Community Research

Criteria applicable to all research	Explication of context and purpose Use of appropriate methods Transparency of procedures Ethical treatment of participants Importance of findings
Research-relevant community psychology values and principles	Sensitivity to people's contexts Respect for diversity among people and settings Addressing competencies Promoting empowerment Giving voice to traditionally underrepresented Promoting social justice Research using multiple methodologies
Criteria specifically applicable to quantitative research	Reliability and validity of measurement Internal validity External validity Statistical conclusion validity
Criteria specifically applicable to qualitative research	Disclosure of perspective Grounding interpretations in the data Coherence of interpretive framework Credibility checks (e.g., consensus; auditing; respondent

Note. From "Quality criteria under methodological pluralism: implications for conducting and evaluating research", Barker & Pistrang, 2005, p. 204.

Barker and Pistrang (2005) have discussed criteria that can be applicable to all research, and criteria specifically applicable to quantitative and qualitative research, as quality standards to judging method choices in community research (Table 3). Therefore, in order to ensure research rigor in qualitative inquiry, the researcher has to disclose relevant personal background in relation to the study's topic, to ground the new ideas in the data, and presenting them within a logically coherent structure (Denzin & Lincoln, 2005).

However, while interpreting, the researcher must follow strict procedures like consensus, auditing, asking respondents to validate analysis, or triangulating using more than one source of information.

CBPR in Practice: Fostering Capabilities and Social Integration Study

In the past two decades, the recovery paradigm has emerged as the orienting principle to the organizations and support services for people with mental illness (Anthony, 1993, 2000). Recovery is a deeply personal process of rediscovering one's new sense of identity and personal strength for living, participating and contributing for the community (Ahern & Fisher, 1999; Deegan, 1996). Davidson, Ridgway, Wieland and O'Connell, (2009) questioned how the mental health field should transform itself to be consistent with this emerging vision of recovery.

These authors as well as Hopper (2007), Ware, Hopper, Tuggenberg, Dickey and Fisher, (2007) and Shinn (2009) propose the adoption of the Capabilities Approach (CA), conceived by Amartya Sen (1993), to put in practice the purposes of recovery mental health system transformation.

The capability to do and to be might signify the freedom to achieve more options and choices for lives of people with mental health problems (Davidson et al., 2009). The capabilities framework directs thought and action to the context and to the options (functional freedoms) available to people in disadvantage; so it opens interesting perspectives for analyses and interpretation on the ecological theory, on a multi-level perspective. Focusing on a macro level analysis, the CA framework should be a useful measure for the comparison between contexts. Therefore, the community services must facilitate the access and people's full participation in the community contexts, as opposed to segregation in separate mental health services.



Objectives and methods

The research objectives are: to study how a community-based organization promotes the individual capabilities and community integration of people with mental illness experience; and to develop an instrument to compare capabilities' promotion in mental health community settings. The research design is a quasi-experimental, comparative study, using a participatory and pluralistic approach.

Context Description

The context under study, AEIPS-Associação para o Estudo e Integração Psicossocial, has a long history of work in the mental health area, within the recovery paradigm for the promotion of individual capabilities and community integration. It is a mental health community based organization (MH-CBO), operating since 1987 and created by consumers, professionals, and families to develop different types of support in order to facilitate community integration and to challenge the deinstitutionalization in Portugal. In the last 10 years the application of ecological and recovery approaches has contributed to the organizational program's transformation into a community-oriented mental health service, and to support consumers with mental illness experiences in terms of housing, employment, and to enhance access to community facilities like schools, health centres and other social resources (Ornelas, Duarte, & Jorge-Monteiro, in preparation).

AEIPS has created group homes, as housing solutions for 21 adults who had little community support, and also assistance in independent living opportunities. This idea was deepened in the last couple of years in a program to independently house 65 people with mental illness, who have been homeless for an average of more than 6 years, in a housing-first model.

Also to accelerate deinstitutionalization, the organization has created a residential facility for the last group of 24 women and men inpatients at one psychiatric hospital.

After a participative evaluation, AEIPS made major changes towards an organizational collaborative relationship between professionals and consumers, in all decision-making processes and service delivery areas, as well as the establishment of an independent leadership and empowerment program. This consumer program also led the creation of a national network of people with experience of mental illness.

Finally, one distinctive service provided by the organization, is its Supported Employment and Education program, which offer individualized support to people who want to go back to school, at any level of education, or achieve employment in mainstream

businesses in the community, through information about job and educational options, work, and helping in vocational or school requirements and through linking users to resources and opportunities. Ornelas et al. (in preparation), describes extensively this program's characteristics and reviews research evidence on supported employment programs.

Establishing the research partnership

Since its foundation, AEIPS is operating as a community psychology practice in community mental health field (Ornelas, 2008). There is also a long term relationship between the organization and a university (ISPA-IU) for intervention and service learning.

Following the research-intervention strategy proposed by Miller and Shinn (2005), to study successful programs in the community, and to gather practice-based evidence, AEIPS and ISPA-IU agreed to build a collaborative research partnership to study the promotion of individual capabilities and community integration. Therefore, the partners had several meetings in order to define the research problem, identify the objectives, and the design of the study.

Research Team. In order to render effective the participatory process, a research team was structured, being composed by three researchers from the university in partial dedication, a fulltime research grantee, a consumer with a research contract, and co-researchers from the organization (consumers and professionals), which number varies depending the study phase. All stakeholders were involved in all tasks of the process, such as, conducting the focus groups, meetings with steering committee, analyzing data, literature review.

Steering Committee. The steering committee is another participatory structure that comprehends the team members, the MH-CBO representatives (2 consumers and 2 professionals), and an external consultant from Vanderbilt University, in the United States, who is a senior researcher in community psychology. The steering committee's main responsibilities are: procedures' supervision (e.g. ethical approval and written consent), helping with new ideas, making decisions, assuring reciprocity, and supporting commitment between participants.

Moreover, the participatory process gives more visibility to the organizational and experiential knowledge of people with mental illness problems, into the research partnership.



Qualitative Participatory Methodology

First task. In a preliminary phase of the study, the objective was to gather qualitative data from the context under study and its participants, concerning community integration and capability gains. Firstly, to approach the users at the organization a presentation at the weekly general meeting was made, where the research team described the research partnership, objectives, the specific proposal of the instrument's construction, and invited them to collaborate in the study. The research team held seven focus group sessions, in two community settings (AEIPS and similar MH-CBO), involving a total of 50 consumers/users attending the programs in those particular days. Groups with a maximum of four participants were created, to give them the opportunity to identify gains, at several levels, in their course and in the service (e.g. education, employment, housing, wellness and relationships and organizational and community participation domains). Each group elected one spokesperson that presented the gains identified by all participants. Simultaneously the team registered the outcomes in electronic format while projecting the data.

Second task. The qualitative data was primarily analyzed throughout twenty review meetings between the team and steering committee members, involving at least 3 consumers and 2 academic researchers in each session. The intention was not to find the most frequent items, but rather the partnership wanted to include all the diversity found in the process.

The process was conducted in order to achieve consensus, firstly about selecting the content units, according to the domains discussed in focus groups, and secondly organizing separate lists of related content.

Third task. This phase corresponded to the construction, per se, of the capabilities gains questionnaire. The steering committee held twelve meetings to review the data according to the capabilities framework, in order to create a user capabilities-oriented measure, in community mental health services. That is, to merge data found with Nussbaum's 10 Central Human Capabilities List (Table 4). The questionnaire proposal was then subjected to testimonial validity, from fifteen participants, for contents adequacy and comprehension proficiency. The measure to assess capabilities, fostered by community settings, will be integrated in a multi-method approach in further phases of the study.

Conclusion

Supported by the literature on community psychology research approaches, the study described was anchored in values of collaboration and ecological perspective, by focusing on context of individual-community organization relationship.

Table 4

The Central Human Capabilities

Capability	Description
Life	Being able to live to the end of a human life of normal length; not dying prematurely.
Bodily Health	Being able to have good health, including reproductive health, to be nourished; to have adequate shelter.
Bodily Integrity	Being able to move freely from place to place; being able to be secure, including sexual assault, child sexual abuse, and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
Senses, Imagination and Thought	Being able to use the senses, to imagine, think and reason – and to do these things in a “truly human” way, informed and cultivated by an adequate education. Being able to use imagination and thought. Being able to have pleasurable experiences, and to avoid non-necessary pain.
Emotions	Being able to have attachments to things and people outside ourselves; to love and grieve, to experience longing, gratitude, and justified anger.
Practical Reason	Being able to form a conception of the good and to engage in critical reflection about the planning of one’s life. (the liberty of conscience)
Affiliation	a) Being able to live with and towards others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to have the capability for both justice and friendship. b) Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being. This entails, at a minimum, protections against discrimination on the basis of race, sex, sexual orientation, religion, caste, ethnicity, or national origin. In work, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.
Other Species	Being able to live with concern for and in relation to animals, plants and the world of nature.
Play	Being able to laugh, to play, to enjoy recreational activities.
Control over one’s Environment	a) <i>Political</i> - Being able to participate effectively in political choices that govern one’s life; protections of free speech and association. b) <i>Material</i> - Being able to hold property (both land and movable goods, not just formally but in terms of real opportunity; and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others.

Note. Adapted from “Women and human development: The capabilities approach”, Nussbaum, 2000.

Therefore, guided by community needs, a university-community research partnership was developed to advance the knowledge for community mental health practice transformation.



Those community research prepositions have enhanced validity and quality of research through the use of qualitative methodology, and through the participation of consumers and professionals from the organization, as co-analysts in the process of rising the knowledge from the setting into the research process.

In this stage of the study, this collaborative endeavour resulted in the first version of the capabilities-gains questionnaire, for evaluating a community and recovery orientation in mental health organizations.

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